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ABSTRACT

The paper addresses the issue of placement for students with severe and multiple disabilities. Controversies over the principle of least restrictive environment are reviewed; and the implications of the normalization movement and the passage of P.L. 94-142, the Education for All Handicapped Children Act, are summarized. The rationale for integration includes better attitudes, better learning for all children, instruction in living together democratically, and similar levels of expense. Factors contributing to successful integration are considered, including commitment on the part of administrators, positive teacher attitudes, normalized pattern of the school day, structured opportunities for peer interaction, high expectations for disabled and nondisabled students, and opportunities for disabled students to assume leadership and helping roles. (CL)

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PUBLIC EDUCATION FOR CHILDREN WITH SEVERE, PROFOUND, AND MULTIPLE DISABILITIES: THE LEAST RESTRICTIVE ENVIRONMENT

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c Special Education Resource Center

During the past several months a team of researchers, myself included, have been polling educational experts, parents, and state officials across the country in an effort to locate outstanding programs for the most disabled and multiply handicapped children. Our purpose has been to identify and learn about promising efforts to teach children who typically have been excluded from public education. This research has turned up a lot of interesting, perhaps even controversial, evidence of "promising practices".[1]

Initially, we wanted to know "how" to provide quality educational services to the most disabled and multiply handicapped youngsters. But, early in the national search, experts and parents alike began to tell us that it was impossible to look at the question of "how to educate" these students without also asking "where to educate" them. Both the experts and consumers framed the issue in today's special education jargon. They spoke of the "least restrictive alternative", "integration", "segregation", and "mainstreaming".

The more closely we examined this issue of "where", the more obvious it became that most of the "promising practices" were making it possible, often for the first time, for very severely disabled and typical (non-disabled) children and youth to see each other and, at least to some extent, interact with each other. They were attending the same public schools. Yet, the idea of providing severely disabled and multiply handicapped children an education in regular schools is still new and still controversial. We decided to examine that controversy. Basically, we wanted to know, why was this issue of where to educate children so important?

The debate over where to educate children comes up over and over again. One parent of a child with autism explained to us what integration means to her. "My child can talk," she told us. "And there's only one reason why he can. It's because of the other children. The typical children kept coming up to him and talking to him and demanding that he talk. They knew how to get an answer from him and they wouldn't let him get away with a single syllable response. Now I ask you," she says rhetorically, "what teacher or teachers could do that for my son, much less for a whole class of kids with autism? That's just not realistic." This mother told us that one day her son was saying, "cran, cran, cran." Several other students in his class -- he attends a

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1. If you are interested in receiving reports on this research, write to Stanford Searl, The Special Education Resource Center, Syracuse University, Rm. 400 Huntington Hall, 150 Marshall St., Syracuse, New York 13210.

unique program which integrates autistic and non-disabled students in the same elementary class in a ratio of four disabled to fourteen non-disabled students. with one teacher and two aides -- would not get him cranberry juice until he said "cranberry juice". And he did.

It has been five years now since Congress passed the Education for All Handicapped Children Act (Public Law 94-142). Yet most public schools in America do not yet have special programs for autistic children. Only one state, North Carolina, has a statewide system for educating autistic children in public schools. Most states sent autistic children to expensive private and state operated special schools or residential facilities. Some have statewide systems for severely disabled students among whom are included autistic children. These children -- there are estimated to be only four autistic children in 10,000 -- are among the severely disabled. By all accounts, they have difficult problems. So calling for integration of these children or any severely disabled children for that matter in public schools, whether in separate special classes or in integrated ones like that described above, is controversial.

Background to the Debate

Actually, the controversy predates the education rights law. In the early 1950's a South Carolina attorney, speaking in the now famous Brown vs. Board of Education case, warned the Supreme Court that if it prohibited segregation of Black students, it might also open the way for other forms of desegregation. "I am unable to see," he lamented, "why a state would have any further right to segregate its pupils on the ground of sex or on the ground of age or on the ground of mental capacity."

Meanwhile, a few outspoken human service and education experts were raising the same issue, integration versus segregation in their professional meetings and journals. One such expert, speaking at the 1946 International Council for Exceptional Children Convention, lobbied for more integration. He seemed to be asking for just what the South Carolinian feared, integration whenever possible "Without question," he told the international audience, "there should be as little segregation as possible because the child should not be deprived of the socializing influence of the regular school if it is possible to help him in regular groups in regular schools." His argument was basically the same as the one made by the parent of an autistic child. "Disabled students can learn from non-disabled students."

The controversy heated up in the 1960's. A number of special education experts began to seriously question the practice of placing severely disabled students in institutions and in separate schools. They even questioned special education itself. For example, Maynard Reynolds, a leader in the field, wrote in 1962 that "when a special placement is necessary to

provide suitable care or education, it should be no more special than necessary."

In Scandinavia, meanwhile, the term "normalization" was coming into vogue. Bank-Mikkelsen, a Dane, coined the term in 1959. By "normalization" he meant the right of disabled people to have opportunities to live in as normal a fashion as possible. It would not take long -- in fact less than a decade -- for this term to make its way to the United States. America learned about the concept largely through the work of another Scandinavian, Bengt Nirje. Nirje wrote an article on the concept for the President's Committee on Mental Retardation. Then he visited the United States and shared his views on the integration issue. One of Nirje's examples, to illustrate normalization, grew out of a conference held in Scandinavia while he was the Executive Director of the Swedish Association for Retarded Children. At the conference, retarded adults were asked to make requests for policy changes that might affect their lives. In their own words, they asked for normalization. People asked not to be given special preference in receiving housing referrals -- there are housing shortages now, as then, in Sweden. The retarded people also asked that when taken into town, they preferred not to go in large groups but rather wanted to go in twos or threes. And they asked that as adults they not be sent to special camps for the retarded only. They wanted to take their vacations in the standard vacation resorts of Europe, in the same places that typical, non-disabled people vacation.

Where Maynard Reynolds had said in effect, "make services no more special than necessary," Nirje and the normalization advocates were saying, "make services (indeed all of life) as normal as possible." The ideas complemented each other. Thus, when parents of a group of severely disabled children in Pennsylvania went to court to demand the right to education for their children, they also wanted normalization. In legal terms, they asked that their children receive education in the least restrictive setting possible. The court found in their favor:

> It is the Commonwealth's obligation to place each mentally retarded child in a free, public program of education and training appropriate to the child's capacity, within the context of the general educational policy that, among the alternative programs of education and training required by statute to be available, placement in a regular public school is preferable to placement in a special public school class and placement in a special public school class is preferable to placement in any other type of program of education and training.

Almost as soon as the term "least restrictive environment" entered the field of education it sparked a debate. Some experts charged that it would lead to disaster. Children with disabilities, even children with severe disabilities like

profound deafness, could legally be left to their own devices, adrift in public school classes with little or no special education services. Albert Shanker, a prominent teacher union leader, suggested that children with severe medical needs would be cast upon ill prepared teachers. He warned that special educators would find themselves out of work. He characterized the "mainstreaming" as one more instance of schools being asked to do things that were beyond their means. Others argued that you should not push for integration unless you had evidence that students learned better as a result of it. Still others feared that "least restrictive environment" meant trading off quality.

Most of these criticisms misstate the real meaning of "least restrictive environment". The concept simply means that when a school district educates a child with a disability, it should do so in a way that least limits or most enhances a child's opportunity to be near and interact with all other children. It does not say "throw away special services." It does not say integrate at all costs, even if it means damaging the child. It does not say "integrate but do not give the necessary support services to the teachers who make integration possible."

Public Law 94-142 defines the issue this way:

> to the maximum extent appropriate, handicapped children, including children in public or private institutions or other care facilities, are educated with children who are not handicapped; and that special classes, separate schooling, or other removal of handicapped children from the regular educational environment occurs only when the nature or severity of the handicap is such that education in regular classes with the use of supplementary aids and services cannot be achieved satisfactorily..... (20 U.S.C. 1412(5) (B).

In other words, the law says, integrate as much as possible and appropriate.

"How much integration is appropriate?" As we spoke with educators and parents around the country about where best to serve children and youth who have severe and multiple disabilities, no one suggested to us that segregation was a preferred approach. Some said they were not sure which was better, integration or segregation. But the majority of people we spoke with, both parents and experts favored integration. Through conversations across the country and through our review of published articles, we have recorded what seems to be the major reasons for bringing special programs for even the most disabled students into regular public schools.

Why Integrate

Better Attitudes:

Disability is a personal characteristic, like hair color, weight, height, eye color, and personality. But disability, qualities such as race, place of birth, political and religious beliefs and wealth (or poverty) may be viewed negatively. By the same token, people who have disabilities may be viewed negatively. It comes out in unfriendly labelling: "he's a retard"; "that deaf mute"; "blind as a bat."

No natural law says, "people with disabilities are not as good as people without disabilities." And, no natural law says people with disabilities are better or more blessed than anyone else either. It is a well known fact that different societies treat disabilities differently -- some negatively, some not. In other words, society decides how to treat disabilities. And we pass these attitudes on, from adults to children.

The best way to change bad attitudes is by challenging them. Research shows that the single most effective way to help people overcome their prejudices about disabilities is by purposely bringing disabled and non-disabled people together. As noted researcher, Robert Kleck, put it, "the legislation that will make disabled people visible -- in schools, in busses, in apartment buildings -- will bring some good with more contact. One thing my research tells me is that frequency of contact improves one's comfort with handicapped people."

Unfortunately, many children develop their knowledge of disabilities on the basis of knowing or meeting one disabled person. That's what researcher and author, D. Alan Brightman, found in his interviews with school children. No wonder children develop stereotypes. After all, people with disabilities are as different from each other as any group of people are different from each other. Imagine if men based all their attitudes about women on the basis of knowing or meeting one woman. Only repeated opportunities for people with disabilities and people who have no disabilities to get to know each other can break down bad attitudes.

Advocates for school integration point to a flood of teaching materials, including books, films, filmstrips, puppet shows, and records, all oriented toward helping disabled and non-disabled children to get to know each other. Such materials, they say, makes it easier than ever to build healthier attitudes.

Better Learning:

One reason often advanced for segregating certain groups of children is "to provide something unique," something that can be taught best in a specialized program or center. For example, segregate blind children to teach them Braille; segregate non-verbal children to teach them how to use a handy voice communicator. But, increasingly, educators and parents alike are

asking, "how much segregation is necessary?" What about lunch time, leisure time, sports, reading, art, school assemblies, field trips, and other school activities? Why can't nearly all children participate in these?

Curriculum specialists, the people who develop ways for teaching children, are finding that many kinds of special education occur best in regular, integrated schools and communities. It appears that while certain learning activities occur best through individualized teaching and by so-called subject grouping (e.g., Braille, sign language) many other activities (e.g., mobility training, vocational education, and community living skills) demand integration. How better for a child with severe retardation to learn when to laugh, how to dress, and how to walk than to observe his or her non-disabled peers? Many of the nationally recognized teaching models for severely disabled students require frequent interaction with non-disabled students. In fact, in 1979, the Association for the Severely Handicapped, an association comprised of teachers, teacher trainers, researchers, and parents passed a resolution calling for an end to all separate schools for the disabled only. The association found that while special classes and resource programs are often useful, indeed advantageous, these can be provided in regular school so that there can also be a good deal of integration.

Teach Democracy:

Two well known analysts of American education, Seymour Sarason and John Doris, have said that society expects schools to accomplish two tasks: a) to teach students how to think and b) to teach democracy. Typically, schools have done better at the first task than the second. They have taught children how to think better than they have taught democracy.

The best way to teach democracy is to practice it. If schools practiced democracy, students could learn by doing. A central principle behind democracy is that all people should have equal opportunities to develop to their fullest potential. In education, this means black and white, male and female, and disabled and non-disabled students going to school together. Through school integration, non-disabled and disabled students will learn to live together in society as adults.

No More Expensive:

Integration, but at what price? Americans have never ignored the matter of expense when it came to planning social programs. How much will it cost for health care of older people? How much for child welfare? How much for food stamps? How much for new highways? How much for farm price supports? And how much for mass transit? It is natural that people ask, how much does integration cost?

The courts have said that school should provide disabled children with their share of education in the most appropriate way. And, the courts have said a school district cannot use lack of money as an excuse for not providing a program. What kind of program will a school district provide? In deciding that, schools will consider cost.

The important point here is that researchers have not come up with evidence that segregated schooling for disabled students only is cheaper or better than integrated schooling. In fact, our own surveys of promising practices suggest that these much talked about model programs are not expensive when compared to many of the segregated programs. The statewide autism program in North Carolina, for example costs approximately $5,500., including an extensive diagnostic and assessment program, family training and support services, research teacher training, school consultation, classroom teacher, and special support services in schools. While that seems like a lot of money when compared to the average cost of educating a non-disabled child, ranging anywhere from 900 to 2500, it is incredible low. Compare the $5,500 figure for those integrated public school programs with the $50,000 paid for some private special school programs.

Similar evidence exists for other disability groups. For example, separate institutions use up anywhere from $20,000. to $116,000. per retarded child served. Those figures make community living and community education seem like a bargain.

Unfortunately, many states still have laws which encourage school districts to send children away to expensive separate programs. These laws say in effect, "If you provide the school program you pay for it with local tax dollars; if we provide it in a separate state operated or private school, we will pay the total or the major cost with state tax money." Under these provisions, schools which face budget crises, and most do, will think twice before creating their own programs. So, even though integrated programs might be cheaper overall, the school district will ask, "who is paying?"

Social planners have sometimes justified large social programs on the grounds that they save money. The thinking is that big, regional separate programs make it possible to bring together lots of specialists who can work with lots of special needs children in the one location. When researchers have actually studied this question, they have not found these regional, separate programs cheaper. If anything, they have been more expensive. Such special centers usually duplicate existing public school administrative staff, for example. Many even have their own superintendents, their own psychologist and principals, their own social workers. and their own transportation directors. Such programs frequently cause transportation costs to go up. And such programs may maintain their own separate data systems, food service programs, and accounting staff. Moreover, they may duplicate certain expensive equipment and facilities such as

computers, swimming pools, and auditoriums. Thus, one cannot make a simple case that big, separate, special programs are cheaper. Many school districts are finding that they can provide specialized services less expensively by cooperating with each other, by using existing facilities, by avoiding an unnecessary dual administrative hierarchy for special education, by transporting disabled and non-disabled students on the same busses whenever possible, and by securing specialized services from existing community agencies.

The Twin Argument:

Attorney Tom Gilhool and his colleagues at the Public Interest Law Center of Philadelphia talk a lot about the "developmental twin" argument. They ask a simple question. If a child with a particular type of disability can be successfully integrated, either with special services in a regular school or in a regular class, then why cannot all children with the same type and level of disability by similarly integrated. Gilhool has taken that argument to court. He and his colleagues have identified severely disabled students who receive their education in regular public schools. Then he has asked the court, why must another group of students, his clients, remain in separate schools and institutions?

For each child or youth in a segregated school program, one can find a similarly disabled child in an integrated program or school. The children are, in other words, developmental twins. Attorney Gilhool and his colleague, Ned Studmen, have found this evidence sufficient for closing down separate schools. They put it this way, "there is no...reason...---that is, no learning reason and no disability reason---for handicapped only centers, certainly not on the scale they exist now. If a child can come to a school at all, even to a self-contained class in a handicapped only center, he can come to a self-contained class in a normal school. Any teaching technique that can be used in a self-contained class can be used in a self-contained class located in a regular school building." That's the power of the developmental twin argument. In the absence of evidence that children learn better when segregated, the mere existence of integrated programs calls into question segregated centers.

This argument does not say "integrated school programs are always good." It says only, integrated programs can do anything that segregated ones can and a few things more. So, why not work toward making integrated programs the best possible?

Practical Evidence:

When federal courts first said children with disabilities have the right to an education in "the least restrictive environment appropriate" most school districts had no integrated programs for severely and multiply disabled students. A group of researchers in Madison, Wisconsin recently suggested that most

severely disabled students still receive their education in segregated schools. But they also noted that a large number of school districts, including Madison, Wisconsin's, do have integrated programs. And with these integrated schools, teachers and parents have learned a great deal about what makes integration work. Our own surveys of school programs for severely disabled students have provided evidence too. In addition, we have gathered information through another study of successful mainstreaming programs. While neither of these studies is complete yet, it is already clear that certain factors help make integration successful.

1) The principal must believe in integration and must share that belief with teachers and parents.

2) The teachers most responsible for integrating disabled and non-disabled students must view disabled students as individuals and not as people defined only by their disabilities (e.g., "the trainables," "the Down's kids," "the autistics," "the deaf kids.")

3) The pattern of a school day for disabled students should resemble the non-disabled child's school day. Children should arrive and leave at the same time, eat meals together, have roughly the same amount of time for recreation and academics, and so forth.

4) Children should attend schools that include children of their same age.

5) Children should be grouped in classrooms by actual age rather than by so-called developmental or mental age. While some children will need special class placement, they should be grouped with other special needs children of the same or similar age.

6) Faculty and staff need to structure ways for disabled and non-disabled students to come into contact with each other.

7) A school needs adequate staffing.

8) The most vibrant school programs seem to be those which encourage involvement of parents (of disabled and non-disabled student's alike) in school program development and school decision making.

9) The school must ensure the personal safety of all students.

10) The staff and faculty must hold high expectations

for both disabled and non-disabled students.

11) The faculty should avoid unnatural teaching methods which would emphasize differentness of disabled students.

12) The school should make teaching positive attitudes toward differences a regular part of the curriculum.

13) Children with disabilities must have opportunities to assume leadership and helping roles to balance the more dependent roles into which they are so often placed.

The fact that schools have now given us practical evidence that integration can work makes the idea of integration so much more compelling.

Parental and Community Involvement:

When President Lyndon Johnson first established Head Start programs for poor children, educational researchers were called in to evaluate the results. Some experts hoped to prove the programs would help poor children perform better once they got to regular school. But interestingly, one of the most impressive findings of these evaluations was that Head Start caused parents to become more involved in the lives of their children and in school.

Researchers have found a similar effect from the Education For All Handicapped Children Act. Brightman and Sullivan report, "By their own report, these parents have acted more and have believed themselves to have accomplished more on behalf of their disabled children, than was ever the case for most prior to the legislation." Equally important, they found that parents reported thinking more positively about their children's futures in society. Similarly, anyone who has observed the increasing attention of schools to special education cannot help but to have noticed that schools and communities are becoming more involved than ever before in considering and shaping the future role of disabled people in the community. Granted, not all the developments have been positive. But who can argue with the fact that the push for integration has resulted in non-disabled people taking more seriously the needs of people with disabilities?

Conclusion

With all these reasons why integration makes sense, why the controversy? To be sure, some parents and experts still think children with particular kinds of impairments learn better in separate facilities. While there is no hard evidence to support that view, people will probably argue about it for some time to come. Some people seem to resist immediate integration on the

grounds that the best change is that which occurs slowly. Perhaps the most obvious reason for the controversy, however, is that change never comes easily or even quickly. No matter how good the idea, it challenges standard operating procedure. It calls on all of us to change our ways.

Therein lies the challenge. The question of Where to provide an education for severely and multiply disabled students is being answered over and over again---in quality integrated programs, in regular schools. The question now is more pragmatic. Can educators and parents create the conditions for change to occur more rapidly? Will states and school districts commit themselves to developing high quality, intensive programs in regular schools, for even the most severely disabled students? Will states ensure equitable funding mechanisms for integrated programs? Will administrators take the lead in promoting integration? Will schools use the newly available teaching materials for attitude change? Will schools reach out to involve parents and communities? The available evidence permits only one answer to these questions. They must!